

'Leaving no stone unturned': contesting the medical care of a seriously ill child

Article (Accepted Version)

Bridgeman, Jo (2017) 'Leaving no stone unturned': contesting the medical care of a seriously ill child. *Child and Family Law Quarterly*, 29 (1). pp. 63-84. ISSN 1358-8184

This version is available from Sussex Research Online: <http://sro.sussex.ac.uk/id/eprint/67304/>

This document is made available in accordance with publisher policies and may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher's version. Please see the URL above for details on accessing the published version.

Copyright and reuse:

Sussex Research Online is a digital repository of the research output of the University.

Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable, the material made available in SRO has been checked for eligibility before being made available.

Copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

‘Leaving No Stone Unturned’¹: contesting the medical care of a seriously ill child

Jo Bridgeman*

Abstract

Recent cases concerning disagreements over the medical treatment of a child with cancer prompt consideration of the effectiveness of the courts in the resolution of conflict over the best interests of a seriously ill child. With reference to studies of parents whose child has received treatment for cancer, this article explores parental experiences of the increased vulnerability and dependency of their child, intensification of the parenting role, loss of control and dependency upon healthcare professionals. With a lengthy treatment plan delivered by a multi-disciplinary team causing serious and distressing side-effects in the effort to save life, parental concerns can arise about their child’s care from which disputes over treatment develop. In their endeavours to secure the very best treatment for their child, ‘leaving no stone unturned’, parents may reject the advice of the treating team. This article examines recent cases concerned with the treatment of a child for cancer within the context of the wider body of case law in which a dispute has developed from a disagreement between parents and professionals over the medical treatment of a young and dependent child. It argues that if parents, determined to secure what they consider to be best for their child, cannot agree with the treating team they are unlikely to be persuaded that the judge knows what is best for their child and resist the imposition of the decision of the court. In such circumstances, court intervention may protect doctors from legal action but not protect the best interests of the child. It is argued that rather than emphasise, as the current legal framework does, the need for court orders in cases of disagreement, emphasis should be placed upon the legal duties of professionals to work together with parents to secure the best interests of the child and the responsibilities of the Trust to support both in this endeavour taking all possible steps to attempt to resolve the disagreement without the need for court intervention.

Keywords

Children’s medical treatment; Parental/professional disputes; Parental responsibility; Conflict over care

A Contesting the medical care of a seriously ill child

Disagreement between healthcare professionals and parents responsible for making decisions about a child’s medical treatment is a fairly common occurrence, particularly when difficult decisions have to be made about the care of children with life-limiting conditions or acute illness.² Escalation of the disagreement to a conflict requiring court resolution is comparably rare. This article considers court intervention in four recent cases concerning a conflict between parents and professionals over the medical treatment of children with cancer, *SR*,³ *King*,⁴ *JM*⁵ and the unreported case of Alex Elliot.⁶

* Professor of Healthcare Law and Ethics, Sussex Law School, University of Sussex. I would like to thank the two anonymous reviewers of an earlier draft of this article for their constructive criticisms and perceptive comments.

¹ This metaphor is used repeatedly in accounts from parents of their experiences of caring for a child undergoing treatment for cancer.

² Liz Forbat, Bea Teuten, Sarah Barclay, ‘Conflict escalation in paediatric services: findings from a qualitative study’ (2015) 100 *Arch Dis Child* 769-773 doi:10.1136/archdischild-2014-307780.

³ *An NHS Trust v SR* [2012] EWHC 3842.

⁴ *In the Matter of Ashya King (a Child)* [2014] EWHC 2964.

⁵ *Re JM (A Child)* [2015] EWHC 2832.

⁶ Nadeem Badshah, ‘Surgeon ‘wanted parents of dying boy kept in dark’ The Times, 20 June 2015,

The earliest cases of judicial involvement in decisions about the treatment of children with cancer concerned the powers of the court, and the appropriate procedure, under the Children Act 1989, to give doctors the authority to administer blood refused as part of an otherwise accepted treatment package due to parental religious beliefs as Jehovah's Witnesses.⁷ These cases were resolved by the court providing doctors with the authority to administer treatment in an immediately life-threatening situation whilst respecting the preferences of parents where reasonably practicable in non-life-threatening situations.⁸ Quiet, yet determined, disagreement sums up the case of *Re E* in which Ward J concluded that 15 year-old E lacked the capacity to give a valid refusal of consent to the administration of blood products in the treatment for leukaemia and authorised the administration of blood as in E's best interests.⁹ As is well known, upon reaching his 18th birthday, E refused to consent to the further administration of blood and died.¹⁰ The only possible conclusion is that he remained unconvinced that the decision of the court reflected his best interests.

When, in 1995, Jaymee Bowen's father challenged in the courts the Health Authority's decision not to fund further treatment for leukaemia, in an attempt to secure the treatment which offered the only hope of prolonging his daughter's life, he challenged then dominant norms of the provision of medical treatment in the UK's publicly funded health service. As Ian Kennedy had observed, for example in his 1980 Reith Lectures subsequently published in *The Unmasking of Medicine*,¹¹ at that time medical paternalism prevailed: the view was that the doctor knew best and medical advice, decisions and practices were not to be questioned. The legal basis for doing so was unclear; the information base for doing so difficult to access. Difficult decisions of medical practice which also involved social, moral, political, economic and legal issues should not, Kennedy argued, be left to the individual practitioner¹² nor were they best reached in 'hastily convened hearings' of the court.¹³ Kennedy argued for the creation of a Permanent Standing Advisory Committee with the remit to develop 'a comprehensive Code of Practice governing the ethics of medical practice',¹⁴ which would provide 'the basis for a relationship of partners in which trust can exist'.¹⁵ He argued that a Code of Practice would assist doctors to guide and explain their position to patients and would offer patients a basis from which to assess the doctor's conduct.¹⁶

http://www.thetimes.co.uk/tto/health/news/article4475603.ece?CMP=OTH-gnws-standard-2015_06_20 [last accessed 27/10/16]. A fifth case, in which MacDonald J authorised the withholding of active treatment and the provision of palliative care to a child who had received treatment for bone cancer first diagnosed in 2012, was unreported and received little public attention, 'Dying boy's parents lose palliative care court fight', BBC News, 4/11/16, <http://www.bbc.co.uk/news/uk-37878211> [last accessed 9/11/16].

⁷ *Re S (A Minor) (Medical Treatment)* [1993] 1 FLR 376, *Re R (minor) (Blood Transfusion)* [1993] 2 FLR 757.

⁸ Setting the terms of the order where authorisation is required for the administration of blood, for example, *M Children's Hospital NHS Foundation Trust v Mr and Mrs Y* [2014] EWHC 2651; *Birmingham Children's NHS Trust v B and C* [2014] EWHC 531.

⁹ *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386.

¹⁰ Noted by Johnson J in the subsequent case of *Re S (A Minor) (Medical Treatment)* [1994] 2 FLR 1065, concerned with the competence of a teenager to refuse her consent to the administration of blood in the ongoing treatment of thalassaemia.

¹¹ Ian Kennedy, *The Unmasking of Medicine*, 1981, revised 1983.

¹² Ian Kennedy, 'What is a Medical Decision?' in *Treat Me Rights: Essays in Medical Law and Ethics*, 1988, 19-31.

¹³ Ian Kennedy, *The Unmasking of Medicine*, 1981, revised 1983, 126.

¹⁴ Ian Kennedy, *The Unmasking of Medicine*, 1981, revised 1983, 130.

¹⁵ Ian Kennedy, *The Unmasking of Medicine*, 1981, revised 1983, 128.

¹⁶ Ian Kennedy, *The Unmasking of Medicine*, 1981, revised 1983, 128-9.

In the absence of such a Committee or Code of Practice disagreements between parents and professionals about the medical treatment of a child are referred to court for resolution. Research by Forbat et al has traced the conflict pathway from parental concerns about their child's care to the breakdown in the parental/professional relationship to referral to court.¹⁷ Conflict in paediatric care was described by professionals in one study as a breakdown in communication and/or trust resulting in the marginalisation of the interests of the child either because professionals are not able to provide the care they consider optimal or because the deterioration in the relationship with parents affects professional ability to provide care to the child.¹⁸ Conflict over treatment was most likely to arise where there is 'poor prognosis, complex multidisciplinary approaches and high levels of uncertainty'.¹⁹ The most common causes of conflict were identified as communication breakdown (22%), disagreements about treatment (13%) and unrealistic expectations (11%).²⁰ Care of a child with, for example, cancer requires the expertise of multi-disciplinary teams of professionals creating the potential for parents to feel they are being provided with inconsistent advice about their child's treatment, undermining their trust in the professionals upon whom they depend.²¹ Treatment of childhood cancer is a long process during which parents will undertake their own research.²² This may reveal 'success stories' of alternative treatments, legal disputes over care, charities raising funds for research into more effective and less damaging treatment,²³ or offering financial support for

¹⁷ Liz Forbat, Bea Teuten and Sarah Barclay, 'Conflict escalation in paediatric services: findings from a qualitative study' (2015) *Arch Dis Child*, doi:10.1136/archdischild-2014-307780.

¹⁸ Sarah Barclay, 'Recognizing and Managing Conflicts between Patients, Parents and Health Professionals' (2016) 26 *Paediatrics and Child Health* 314.

¹⁹ Liz Forbat, Charlotte Sayer, Phillip McNamee, Esse Menson, Sarah Barclay, 'Conflict in a paediatric hospital: a prospective mixed-method study' (2016) 101 *Arch Dis Child* 23–27, doi:10.1136/archdischild-2015-308814.

²⁰ Liz Forbat, Charlotte Sayer, Phillip McNamee, Esse Menson, Sarah Barclay, 'Conflict in a paediatric hospital: a prospective mixed-method study' (2016) 101 *Arch Dis Child* 23–27, doi:10.1136/archdischild-2015-308814.

²¹ Liz Forbat, Bea Teuten, Sarah Barclay, 'Conflict escalation in paediatric services: findings from a qualitative study' (2015) 100 *Arch Dis Child* 769–773 doi:10.1136/archdischild-2014-307780. Brett King explained this was one reasons for their uncertainty about Ashya's post-operative treatment, Naveed King, 'Real Story of Ashya King', www.youtube.com/watch?v=14ETQn9ZPwk, posted 30/8/14, [last accessed 21/10/16].

²² It was through her own research that 14 year-old JS, receiving palliative care after unsuccessful cancer treatment, discovered cryonics. Her father, who had not been actively involved in her upbringing disagreed with her mother's agreement that her body should be preserved after her death in the hope of advancements in the treatment of cancer identifying a cure at some point in the future. JS therefore applied for a specific issue order, which Peter Jackson J made, *Re JS (Disposal of Body)* [2016] EWHC 2859.

²³ The Children's Cancer and Leukaemia Group is a charity which funds research and provides information to families, offers expert advice to government and a professional association to share best practice, <http://www.cclg.org.uk/About-Childhood-Cancer> [last accessed 3/8/16]. A number of charities have been established in memory of a child whose treatment was unsuccessful. Christopher's Smile was established in memory of Christopher who died in 2008, just days before his sixth birthday, to raise funds for targeted drugs to treat brain cancers without devastating side effects, www.christopherssmile.org.uk/ [last accessed 1/9/16]. Abbie's Army was established in memory of Abbie Mifsud, who died from an inoperable brain tumour in September 2011, aged 6, to raise awareness and fund research and new treatments for the brain cancer, Diffuse Intrinsic Pontine Glioma, www.abbiesarmy.co.uk [last accessed 1/9/16]. Blue Skye Thinking was established in memory of Skye Hall, who died a year after receiving the diagnosis of brain cancer in August 2013 at the age of 5, to raise

parents pursuing treatment abroad.²⁴ Comparing the treatment provided to their child with that given to others on the same ward, to treatment offered at other hospitals or treatments available abroad may raise concerns, perceived or real, about the quality of care provided²⁵ or that treatment is limited by available resources. The research by Forbat et al observed that where the conflict escalated a breakdown in trust led to positions becoming entrenched, parents sought to micromanage treatment, both parents and professionals avoided discussing the issue upon which they were disagreed and each side looked for support for their position. Eventually, the relationship deteriorated, the child was no longer the focus as the conflict took over and threats were made of reporting to the media or GMC or referral to court.²⁶ Court intervention, however, can 'result in entrenchment and a further escalation of already strongly held opinions'.²⁷

Disagreements about the medical treatment of a seriously ill child originate in the specific context of parental responsibility of intensive parenting, focused upon the specific needs of their child, dependent in a public institution upon the expertise of others to provide their child with the highest possible care. This article considers the practical reality of parental responsibilities to a seriously ill child with reference to studies of parental care of children with cancer. It does so in order to consider the insights these studies offer as to why parents may question the quality of treatment provided to their child, which may lead them to question the professionals upon whom they depend and to a breakdown in trust and the development of a conflict between those responsible for the care of a seriously ill child.

As the cases considered below demonstrate, where the court is involved, it usually authorises the medical treatment preferred by the child's treating doctors.²⁸ In contrast with cases in which the court is asked to authorise the withholding or withdrawal of medical treatment from a child with a life-limiting condition who is hospitalised and dependent upon aggressive medical treatment, in which the predicted crisis occurs and the court authorised course is adopted,²⁹ in the cases considered

money for research into treatment for childhood brain tumours, www.blueskyethinking.org [last accessed 1/9/16].

²⁴ The charitable purpose of Kids 'n' Cancer is to raise funds to help UK children receive Proton Beam Therapy abroad, <http://www.kidsncancer.org.uk/> [last accessed 1/9/16]. After being turned down for NHS funding, in April 2014, the parents of two year-old Freya Bevan raised £110,000 to take her abroad for proton beam therapy. Kids'n'Cancer underwrote any shortfall in the costs of her treatment in Oklahoma (Helen Barnett, 'We begged doctors to save our baby but instead it was down to us to raise £105k', *Express Online*, 21/6/15, <http://www.express.co.uk/news/uk/585983/We-begged-doctors-to-save-our-baby-but-instead-it-was-down-to-us-to-raise-150k> [last accessed 27/10/16]. The charity offered to pay for Ashya King's treatment, Paul Peachey, 'Ashya King: the five-year-old and his parents are reunited as charity offers to pay for medical care', *The Independent*, 3/9/15, <http://www.independent.co.uk/news/uk/home-news/ashya-king-the-five-year-old-and-his-parents-are-reunited-as-charity-offers-to-pay-for-medical-care-9710025.html> [last accessed 27/10/16].

²⁵ *Re TM* [2013] EWHC 4103, Holman J had only sketchy details of the episode which had undermined TM mother's trust in her paediatric surgeon, [12], [23].

²⁶ Liz Forbat, Bea Teuten and Sarah Barclay, 'Conflict escalation in paediatric services: findings from a qualitative study' (2015) *Arch Dis Child*, doi:10.1136/archdischild-2014-307780.

²⁷ Simon Meller, Sarah Barclay, 'Mediation: an approach to intractable disputes between parents and paediatricians' (2011) 96 *Arch Dis Child* 619-21, 619.

²⁸ Rob Heywood, 'Parents and Medical Professionals: Conflict, Co-operation and Best Interests' (2012) 20 *Medical Law Review* 29-44.

²⁹ An exception is Charlotte Wyatt. Decisions about Charlotte's medical care were referred to court on numerous occasions in the first three years of her life in the context of a protracted and impassioned conflict of views between her parents and treating

here, court intervention does not ensure that the child immediately gets the treatment the court has authorised. If parents cannot agree with the child's treating team, they are unlikely to be persuaded by the judgment of the court which fails to consider parental experiences or address parental concerns. Parents may feel that they have no option but to ignore the ruling and orders of the court and take matters into their own hands in their relentless pursuit to secure their child's best interests. The court then fulfils no function other than to 'protect' professionals from 'claims by the litigious'.³⁰ It is argued that rather than, as the current law does, emphasise the need for disagreements over treatment to be referred to court, emphasis should be placed upon the legal duties of professionals to work together with parents to secure the best interests of the child and the responsibilities of the Trust to support both in this endeavour taking all possible steps to attempt to resolve the disagreement without the need for court intervention.

A Parental Responsibility for a seriously ill child

As is well known, the duty to seek, and to make decisions about, medical treatment for a child are aspects of parental responsibility. Ward LJ, in the conjoined twins case, *Re A*, observed that, 'in the current law the right and the duty to give consent to medical treatment is an incident of parental responsibility vested in the parent'.³¹ Parental right is subordinate to the welfare of the child and subject to review by the court.³² Defined by section 3(1) of the Children Act 1989 parental responsibility is a legal concept which enables the parent to meet their duties to the child,³³ taking practical responsibility 'for the safety, nurture and upbringing of the child'.³⁴ The Law Commission considered that framing the legal relationship between parent and child in terms of responsibility would 'reflect the everyday reality of being a parent'.³⁵ Parental responsibility is responsibility to their child. Described as a 'sort of trusteeship over the child',³⁶ holders of parental responsibility are required to 'adopt a child centred approach to their responsibilities in meeting the child's welfare'.³⁷ However, the law gives parents 'a large measure of autonomy in the way in which they discharge their parental responsibilities'³⁸ from routine day-to-day matters to important decisions which will have major consequences for the child's life.

The Law Commission advised against a detailed definition of parental responsibility seeing its content as dependent upon all the circumstances including the

doctors, 'Children with Severe Disabilities and Their Families: Re-examining Private Responsibilities and Public Obligations from a Caring Perspective' in *Law and Bioethics: Current Legal Issues 2008*, Michael Freeman (ed), OUP (2008) 358-375; Margaret Brazier, 'An Intractable Dispute: When Parents and Professionals Disagree' (2005) 13 *Medical Law Review* 412-418.

³⁰ *In Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1993] Fam 64, 78.

³¹ *In Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] Fam 147, 178.

³² *In Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] Fam 147, 179.

³³ *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1986] AC 112, Lord Scarman, 185.

³⁴ Baroness Brenda Hale of Richmond, 'Family Responsibility: Where are We Now?' in Jo Bridgeman, Heather Keating and Craig Lind (eds), *Taking Responsibility, Law and the Changing Family*, Ashgate, 2011, 25-35, 26.

³⁵ Law Commission, *Review of Child Law: Guardianship and Custody*, No 172, 1988, 2.4.

³⁶ Andrew Bainham, 'Parentage, Parenthood and Parental Responsibility: Subtle, Elusive yet Important Distinctions' in *What is a Parent? A Socio-Legal Analysis*, Andrew Bainham, Shelley Day Sclater, Martin Richards (eds), 1999, 35.

³⁷ *Re C (children)* [2016] EWCA Civ 374, King LJ [43], quoting Sharpe J in the Family Court.

³⁸ *Regina v Secretary of State for Education and Employment and Others* [2005] UKHL 15, [72].

age and needs of the child. Parental responsibility is in part legally constructed, in that what parents are expected to do takes some shape from the minimum standards set by legal obligations.³⁹ Parental responsibilities are further socially⁴⁰ and culturally⁴¹ constructed: What parents feel they ought to do and what parents will do in response to the needs of their child will also be formed in light of social and cultural expectations of parenting. But they are also given individual interpretation.⁴² Parents respond, out of love and concern, to the needs of their child doing what they can to achieve the best for the current and future interests of the child in light of a shared past. Parental responsibilities are thus constructed but also responsive, contextual, particularistic and relational.

Where parental responsibility is shared it can either be exercised jointly or alone permitting each person holding parental responsibility to care for the child.⁴³ Judgments in cases concerning the **provision of healthcare** to children occasionally report slightly different positions held by those sharing parental responsibility for a child but, in all cases, it is the absence of agreement to that proposed by the medical professionals which results in the matter being referred to court, rather than a disagreement between holders of parental responsibility.⁴⁴ This was the case even where the parents were disagreed on the post-operative treatment for a cancerous brain tumour of 7 year-old Neon Roberts. His mother wished for him to be provided with alternative, complementary, treatments. Bodey J emphasised that Neon's doctors would have been acting lawfully had they administered the conventional treatment to which his father had given consent but understood the decision of the Trust to secure judicial determination given the seriousness of the issue upon which the parents were disagreed.⁴⁵ Bodey J authorised the conventional treatment as in the best interests of the child and made a further order to ensure that there was no doubt that, in the future, treatment could be provided on the basis of the father's consent alone. That Neon did then receive the conventional treatment was down to his father's co-operation; his mother remained firmly unconvinced.⁴⁶

Reflective of the aims of the Children Act 1989, Baker J in his judgment in the case of Asyha King emphasised that the primary responsibility for the provision of the

³⁹ Baroness Brenda Hale of Richmond, 'Family Responsibility: Where are We Now?' in Jo Bridgeman, Heather Keating and Craig Lind (eds), *Taking Responsibility, Law and the Changing Family*, Ashgate, 2011, 25-35, 27.

⁴⁰ David H J Morgan, *Rethinking Family Practices*, Palgrave Macmillan, 2013, 89.

⁴¹ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1845.

⁴² RN Fiore and HL Nelson, 'Recognition, Responsibility and Rights: An Introduction' in *Recognition, Responsibility and Rights: Feminist Ethics and Social Theory*, RN Fiore and HL Nelson (eds), Rowan & Littlefield Publishers Ltd, Maryland, vii-xi, ix.

⁴³ Children Act 1989, s.2(7); Apart from that 'small group of important decisions made on behalf of the child' entrusted to holders of parental responsibility as long as all with parental responsibility agree but which must be determined by the court in the event of disagreement', *Re J (s 10: Child's Religious Upbringing and Circumcision)* [2000] 1 FLR 571, Dame Elizabeth Butler-Sloss P.

⁴⁴ In comparison with disagreements between holders of parental responsibility upon immunisation as a matter of preventative healthcare, for example in *Re C (Welfare of Child: Immunisation)* [2003] EWHC 1376 upheld on appeal *B (Child)* [2003] EWCA Civ 1148 or the elective procedure of male circumcision as in dismissing appeal from *Re J (Specific Issue Orders: Muslim Upbringing and Circumcision)* [1999] 2 FLR 678 upheld on appeal in *Re J (A Minor) (Prohibited Steps Order: Circumcision)* [2000] 1 FLR 571.

⁴⁵ *An NHS Trust v SR* [2012] EWHC 3842, [3].

⁴⁶ *Against All Odds: The Sally Roberts Story*, <https://sallyrobertsourstory.wordpress.com/sally-roberts-story/> [last accessed 27/10/16].

practicalities of care rested with the child's parents rather than the state.⁴⁷ Ashya's parents had removed him from Southampton General seeking to raise the funds for Proton Beam Therapy in Prague. They believed that this offered him a better chance with fewer damaging side-effects than conventional chemotherapy and radiotherapy as post-operative treatment following surgery to remove a malignant brain tumour. The judge noted that his decision about Ashya's treatment had to be reached according to the welfare of the child, respecting the child's Article 2 and 8 ECHR rights and the

'fundamental principle of family law in this jurisdiction that responsibility for making decisions about a child rest with his parents. In most cases, the parents are the best people to make decisions about a child and the State – whether it be the court, or any other public authority – has no business interfering with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm as a result of the care given to the child not being what it would be reasonable to expect a parent to give.'⁴⁸

What the judge did not go on to say was that, on the prevailing facts, the state was rightly interfering with parental decisions about Ashya's care.

Before turning to a critical analysis of the intervention of the court in the provision of treatment to seriously ill children, the next section considers the experiences of responsibility for the parenting of a child with cancer which offer insights into the reasons why parents may have concerns about their child's medical treatment which may develop into disputes with caring professionals.

A The practical reality of parenting a seriously ill child

Childhood cancer is a critical condition. It is often experienced as one of acute onset although, because the initial symptoms are often shared with far less serious conditions, it can be difficult to obtain a diagnosis. Advances in medical knowledge, science and technology mean that, although prognosis varies between different types, a diagnosis of childhood cancer is no longer inevitably one of a fatal condition. An average of 82% of children will be completely cured.⁴⁹ So, for example, whereas in the 1960s the most common form of childhood cancer, acute lymphoblastic leukaemia, was invariably fatal,⁵⁰ treatment now offers a five year survival rate of about 80%.⁵¹ But the treatment, necessary to save life, is intense, invasive and unpleasant with distressing side-effects and risks damaging long-term effects upon quality of life.⁵² Childhood cancer, as Bridget Young et al observed in their study, thus has the 'potential to disrupt permanently parents' and children's biographies.'⁵³ Immediately upon diagnosis, parents have to make decisions about treatment and may be asked to make other decisions affecting their child's treatment or future such as whether their

⁴⁷ Reflecting both a lack of confidence in the state and an emphasis upon individual responsibility and choice, John Eekelaar, *Family Law and Personal Life*, 2006, 16.

⁴⁸ *In the Matter of Ashya King (a Child)* [2014] EWHC 2964, [31].

⁴⁹ <http://www.cclg.org.uk/About-Childhood-Cancer> [last accessed 3/8/16].

⁵⁰ Mary Dixon-Woods, Duncan Wilson, Clare Jackson, Debbie Cavers, Kathy Pritchard-Jones, 'Human Tissue and "the Public": The Case of Childhood Cancer Tumour Banking' (2008) *BioSocieties* 57-80, 62.

⁵¹ <http://www.cancerresearchuk.org/about-cancer/type/rare-cancers/rare-cancers-name/childrens-cancers#cure> [last accessed 27/10/16].

⁵² Mary Dixon-Woods, Bridget Young and David Heney, *Rethinking Experience of Childhood Cancer: A Multidisciplinary Approach to Chronic Childhood Illness*, 2005, 19

⁵³ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1836.

child should participate in a clinical trial, donate material for scientific research,⁵⁴ or whether reproductive material should be removed, prior to treatment, for storage and use many years later in fertility treatment.⁵⁵

Mothers in the study by Bridget Young et al explained that a cancer diagnosis intensified their child's 'dependency and vulnerability'⁵⁶ and, as a consequence, parenting was intensified.⁵⁷ The authors observed that the mothering role was redefined to one of mothering a 'child in crisis',⁵⁸ which involved 'a fundamental redefining of mother's self-identities and the work of motherhood' which brought with it 'new responsibilities and roles'.⁵⁹ This new self-identity, the researchers observed, was 'reflexively constructed, grounded in the experiential realities of childhood cancer, drawing on culturally prescribed expectations of carers and mothers, and modified through a "cycle of reappraisals and revisions in the light of new information and knowledge".⁶⁰ The ordinary parental responsibilities of caring, protecting, making decisions about welfare and advocating for their child were redefined by their child's serious illness.⁶¹ Life was 'reorganised' around the seriously ill child; mothers explained the need to be physically close to, to be with, their child to enable them to focus upon meeting their needs.⁶² Family life was disrupted; careers put on hold; responsibilities to other family members – parents, siblings, other children⁶³ – accommodated to enable

⁵⁴ Being asked to consent to tissue samples or residual tissue removed in treatment, once clinical use has been exhausted, being placed in the Childhood Cancer and Leukaemia Group tumour bank for the purposes of scientific research, Mary Dixon-Woods, Duncan Wilson, Clare Jackson, Debbie Cavers, Kathy Pritchard-Jones, 'Human Tissue and "the Public": The Case of Childhood Cancer Tumour Banking' (2008) *BioSocieties* 57-80, 63-4.

⁵⁵ Anonymous Two, 'Advocates, Not Problem Parents' (2014) 4 *Narrative Inquiry in Bioethics*, 13-26; Laura Donnelly, 'Scientists grow eggs of 2-year-old girl in 'extraordinary' fertility world first', *The Telegraph*, 1/7/16 <http://www.telegraph.co.uk/news/2016/07/01/scientists-grow-eggs-of-2-year-old-girl-in-extraordinary-fertility/> [last accessed 9/8/16].

⁵⁶ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1837.

⁵⁷ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1844.

⁵⁸ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1845.

⁵⁹ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1837.

⁶⁰ Mary Dixon-Woods, Bridget Young and David Heney, *Rethinking Experiences of Childhood Cancer: A Multidisciplinary Approach to Chronic Childhood Illness*, 2005, 97 ending with a quote from Williams and Calnan, *Modern Medicine: Lay Perspectives and Experiences*, 1996, 1617.

⁶¹ Myra Bluebond-Langner, Jean Bello Belasco, Ann Goldman and Carmen Belasco, 'Understanding Parents' Approaches to Care and Treatment of Children with Cancer when Standard Therapy has Failed' (2007) 25 *Journal of Clinical Oncology* 2414-2419, 2418.

⁶² Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1837.

⁶³ Christopher Riley, 'A Bittersweet Score: A father's account of his family's 20-year journey after a Pediatric Brain Tumor Diagnosis' (2014) 4 *Narrative Inquiry in Bioethics*, 3-6, 5; Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1839.

parents to focus upon responding to and meeting the current and future needs and interests of the seriously ill child.⁶⁴ As parents 'struggle to embrace a new reality',⁶⁵ in the context of intensive parenting, the wellbeing of their child depended upon the delivery of care by experts and the public provision of care:

'in having a child whose vulnerability has been greatly magnified by cancer, other aspects of mothers' roles and obligations are intensified, including their felt responsibility and protection for their ill children, and this takes place against a backdrop of greater complexity, reordered meaning and diminished control.'⁶⁶

Day to day care was reshaped by the particular needs of the seriously ill child, at times hospitalised for treatment at others requiring regular hospital visits for its administration. Staying close to their child, mothers participated in their child's physical care. They learnt new nursing skills; developed expertise in their child's condition, their vital signs and the operation of equipment used to administer treatment. Bridget Young et al observed that mothers were especially concerned to ensure that their child had a good diet and avoided infection suggesting that this was because these were aspects of their child's care over which they could exercise control.⁶⁷ Mothers also told researchers of the emotional work they did, managing their child's emotions and keeping the child occupied in the effort to prevent psychological distress.⁶⁸ But mothers also worked to manage their child's co-operation with medical care, by comforting, supporting, explaining, cajoling, if necessary coercing.⁶⁹ Parents in the study by Joe Kai spoke of an 'imperative responsibility to ensure the safety of their child' and 'to protect [their] child from potential harm' drawing upon their knowledge and experience of the child.⁷⁰ This involved parents in treading a fine line between ensuring that their child got the best possible treatment and that their child did not suffer, assessment of which depended upon close *attentiveness* to their child. Parenting is thus a relational, experiential, *response* drawing upon knowledge of their child, *responding* to facial expressions, their child's demeanour⁷¹ or just their sense of their child. Parents sought to protect their child from harm: harm from the illness, minimising the harm and distress caused by the necessary medical interventions,⁷² or harm from perceived failures in the provision of care. To protect their child from harm, parents monitored their child's

⁶⁴ Jeanne Carlson, 'The Road to Understanding and Acceptance of the Late Effects of Pediatric Brain Tumors and Treatment' (2014) 4 Narrative Inquiry in Bioethics, 21-23, 22.

⁶⁵ Gigi McMillan, 'Confronting Pediatric Brain Tumors: Parent Stories' (2014) 4 Narrative Inquiry in Bioethics, 1-3, 3.

⁶⁶ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 Social Science & Medicine 1835-1847, 1845.

⁶⁷ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 Social Science & Medicine 1835-1847, 1840.

⁶⁸ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 Social Science & Medicine 1835-1847, 1841.

⁶⁹ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 Social Science & Medicine 1835-1847, 1845.

⁷⁰ Joe Kai, 'What worries parents when their preschool children are acutely ill, and why: a qualitative study' (1996) BMJ 983.

⁷¹ David H J Morgan, *Rethinking Family Practices*, Palgrave Macmillan, 2013, 96.

⁷² Joe Kai, 'What worries parents when their preschool children are acutely ill, and why: a qualitative study' (1996) BMJ 983; Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 Social Science & Medicine 1835-1847, 1843.

health and the care provided by the health professionals upon whom they depended,⁷³ they researched medical treatments and reflected upon the care provided as they tried to secure what was best for their child. As Sir Thomas Bingham MR observed in his judgment in the case of Jaymee Bowen, her father had ‘strained every nerve to procure for her the best possible treatment’,⁷⁴ in doing so her family ‘always had, as one would expect, her best interests at the forefront of their minds.’⁷⁵

Usually the exercise of parental responsibility, making decisions about food, clothing, education, religion, treatment of childhood injuries and illnesses, is discharged by parents in the privacy of their parenting relationship without interference. Inevitably, parents will rely upon the expertise of professionals, such as childcare professionals or teachers, in the upbringing of their child. But, parents of a seriously ill child *cannot* meet their child’s needs alone. Parents of a seriously ill child depend upon the guidance, support and expertise of nursing, medical and health professionals to provide their child with the medical treatment and nursing care that they need, care that is beyond the expertise of parents. The nature of the dependency of parents of a seriously ill child upon healthcare professionals is unique in the experience of parenting. Responsibility is shared with professionals who have different expertise and priorities, different roles and legal duties to children in their care so that ‘revolving around the sick child are two different camps of experts, often with different but intersecting agendas, who must figure out how to work with each other.’⁷⁶ The provision of treatment depends upon a partnership of care built upon trust, respect and co-operation.⁷⁷ Parents rely upon professionals to take care in the diagnosis, prognosis, provision of information and advice, and delivery of care to their child. In the vast majority of cases parents will accept explanations given to them by professionals about their recommendations of the best treatment option trusting that the professional, within the publicly funded NHS, is offering the best possible medical treatment and care. It is the responsibility of parents to take the information and advice about the treatment options available and make decisions, ‘perform[ing] a task that is fraught with guilt, doubt, fear and tremendous responsibility’.⁷⁸ From the moment of diagnosis, parents are forced to confront a ‘new reality’ in which ‘unspeakable decisions must be made’.⁷⁹ As Bridget Young et al observed, parents of a child with cancer have to take responsibility for ‘submitting their children’s resistant bodies to unpleasant treatments and manipulating their wills in ways that threatened the entitlements of childhood’.⁸⁰ Parental responsibility in this context requires parents to make decisions about treatment, it also involves advocating for their child, mediating between their child and the professionals and negotiating with a range of professionals upon whom they depend for access to, and provision of, medical treatment.⁸¹ As a parent of a child who had received treatment for cancer explained: ‘As your child’s

⁷³ Agneta Anderzen-Carlsson, Mona Kihlgren, Mia Svantesson, Venke Sorlie, ‘Parental Handling of Fear in Children with Cancer: Caring in the Best Interests of the Child’ (2010) 25 *Journal of Pediatric Nursing* 317-326, 317-8.

⁷⁴ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055, 1066.

⁷⁵ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055, 1066.

⁷⁶ Michael Barraza, ‘The Right Thing’ (2014) 4 *Narrative Inquiry in Bioethics*, 39-42, 41.

⁷⁷ Rob Heywood, ‘Parents and Medical Professionals: Conflict, Cooperation and Best Interests’ (2012) 20 *Med Law Rev* 29-44.

⁷⁸ Michael Barraza, ‘The Right Thing’ (2014) 4 *Narrative Inquiry in Bioethics*, 39-42, 40.

⁷⁹ Gigi McMillan, ‘Confronting Pediatric Brain Tumors: Parent Stories’ (2014) 4 *Narrative Inquiry in Bioethics*, 1-3, 3.

⁸⁰ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, ‘Parenting in a crisis: conceptualising mothers of children with cancer’ (2002) 55 *Social Science & Medicine* 1835-1847, 1845.

⁸¹ Mary Dixon-Woods, Bridget Young and David Heney, *Rethinking Experiences of Childhood Cancer: A Multidisciplinary Approach to Chronic Childhood Illness*, 2005, 101.

chief medical advocate, you will want to turn every stone to maximise success and minimise harm. The doctors might find it exasperating at times, but will, it's hoped, understand you are just doing your job, much as they are doing theirs.⁸² One mother explained the 'constant need to problem-solve and create new, layered strategies. As parents – as primary caseworkers for our children – we are never done.'⁸³

Whilst healthcare professionals provide essential medical knowledge of the child's condition and medical treatment informed by their training and experience of treating children with the same condition, parents have specific knowledge of their own child as an individual material to the child's medical treatment.⁸⁴ Parents, anxious to ensure that their child is provided with the best possible care, explained their concern to ensure that their experiential and intimate knowledge of their child was taken into account in the care provided.⁸⁵ Lack of integration of intimate maternal knowledge with professional and clinical knowledge can be a source of conflict.⁸⁶

In their study, Bridget Young et al found that '[q]uality of communication, information provision and relationships with staff were seen by mothers as playing a crucial role in supporting them as they fulfilled their parental and caring obligations.'⁸⁷ Mothers reported that 'lapses in communication' such as treatments being provided or changed without their knowledge 'made them feel undermined or threatened' particularly where it affected their ability to monitor their child's health.⁸⁸ The authors thus stressed the 'importance of supporting mothers in ways that enable them to fulfil their role as parents of a child in crisis, to the part that services such as information provision can play in helping them meet their obligations, and serves as a reminder that help that might be construed as undermining their role and obligations is likely to be less than welcome.'⁸⁹

The parental responsibility to protect and ensure the safety of their child needs also to be understood in terms of the ongoing responsibilities of parental care, concerned about their child's present and future well-being in light of their shared past:

'Mothers' accounts suggested that the diagnosis of cancer threw into sharp relief the role of mothers as guardians of their child's biography. One aspect of

⁸² Camilla Bustani, 'I know too well the dilemmas facing Ashya's parents: My son had the same kind of cancer as Ashya King and we faced similar medical quandaries, but I bless the NHS', *The Observer*, 7/9/2015, 35, <https://www.theguardian.com/commentisfree/2014/sep/06/ashya-king-brain-tumour-my-son-same-cancer-treatment> [last accessed 27/10/16].

⁸³ Gigi McMillan, 'Confronting Pediatric Brain Tumors: Parent Stories' (2014) 4 *Narrative Inquiry in Bioethics*, 1-3, 2.

⁸⁴ Agneta Anderzen-Carlsson, Mona Kihlgren, Mia Svantesson, Venke Sorlie, 'Children's Fear as Experienced by the Parents of Children with Cancer' (2007) 22 *Journal of Pediatric Nursing* 233-244, 243.

⁸⁵ Mary Dixon-woods, Bridget Young and David Heney, *Rethinking Experience of Childhood Cancer: A Multidisciplinary Approach to Chronic Childhood Illness*, 2005, ch 2; Giles Birchley, "'You don't need proof when you've got instinct!": Gut feelings and some limits to parental authority, in *The Voices and Rooms of European Bioethics*, Richard Huxtable and Ruud ter Muelen (eds), 2015, 120-135.

⁸⁶ Jean Moore and Mary Kordick, 'Sources of Conflict Between Families and Healthcare Professionals' (2006) 23 *Journal of Pediatric Oncology Nursing* 82-91, 84.

⁸⁷ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1842.

⁸⁸ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1842.

⁸⁹ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1846.

this guardianship, ... was mother's work to protect their sick child's identity. In their role as "biography guardians", mothers were particularly concerned about their children's futures: that their children would survive their cancer, and, moreover, that they would survive without significant physical, psychological, or developmental impairment.'⁹⁰

Parents focused upon the needs of their child will do all they possibly can to secure the very best treatment for their child, seeking to maximise their child's chance of survival whilst minimising the damaging effects of life-saving treatment upon future quality of life.⁹¹ Myra Bluebond-Langner et al's study identified the 'relentless efforts' of parents in the quest for the best possible treatment:

'The quest for further cancer-directed therapies or interventions was as much a part of the parents' relentless efforts as sleepless nights, exhausting days, and trips to the hospital. All were expressions of the parents' roles as decision makers, carers, protectors, and advocates: manifestations of a common practice. Illness had become the context that defined what it meant to be a parent. In this experience, their identity as parents was forged. Their task, their responsibility as parents, as decision makers for their child, as they both perceived and enacted it, was to leave no stone unturned.'⁹²

In the unreported case of Alex Elliott, University Hospital Southampton NHS Foundation Trust applied to the Court of Protection for authority to withhold chemotherapy, neurosurgery and other invasive treatment which had been provided following a relapse of brain cancer for which 18 year-old Alex had first received treatment at the age of one.⁹³ His doctors were of the opinion that all medical and surgical treatment options had been exhausted and his condition was deteriorating so that further aggressive treatment was futile, risked causing him distress and he should be allowed to die with dignity.⁹⁴ His parents wanted active treatment to continue believing that he still gained pleasure from life and his family.⁹⁵ Their 'relentless efforts' culminated in a battle through the courts for continued active treatment for their son, as their solicitor Laura Hobey-Hamsher observed:

⁹⁰ Bridget Young, Mary Dixon-Woods, Michelle Findlay, David Heney, 'Parenting in a crisis: conceptualising mothers of children with cancer' (2002) 55 *Social Science & Medicine* 1835-1847, 1843.

⁹¹ In her account, Jeanne Carlson details her grief at the significant and life-long impact of the disabilities caused to her child by life-saving treatment, 'The Road to Understanding and Acceptance of the Late Effects of Pediatric Brain Tumors and Treatment' (2014) 4 *Narrative Inquiry in Bioethics*, 21-23, 22.

⁹² Myra Bluebond-Langner, Jean Bello Belasco, Ann Goldman and Carmen Belasco, 'Understanding Parents' Approaches to Care and Treatment of Children with Cancer when Standard Therapy has Failed' (2007) 25 *Journal of Clinical Oncology* 2414-2419, 2418.

⁹³ Having turned 18, Alex was no longer legally a minor hence the dispute over his treatment was determined in the Court of Protection.

⁹⁴ In February 2015, Hogg J in the Court of Protection authorised the Trust to discontinue chemotherapy but ordered that the shunt and drain should be maintained. A further application in May 2015, before Newton J, in which the hospital sought an order giving them authority to stop maintaining the shunt was withdrawn during the hearing given lack of evidence that maintaining it caused him pain. Alex died in June 2015.

⁹⁵ Patrick Sawyer, 'Judge refuses mother's plea to treat terminally-ill son, saying he should be allowed to die', *The Telegraph*, 14/2/15, <http://www.telegraph.co.uk/news/health/news/11412861/Judge-refuses-mothers-plea-to-treat-terminally-ill-son-saying-he-should-be-allowed-to-die.html> [last accessed 27/10/16].

'Alex's staunchest allies were his parents. Alex was certainly a fighter, but so were they. Their life-long and passionate commitment to fighting for their son knew no bounds. The sadness in this case is that they had to spend the final months of his life fighting just for the treatment necessary to keep him alive.'⁹⁶

A search to satisfy themselves that the medical treatment and care provided to their child is the best possible, in fulfilment of their responsibility to their child, may involve researching alternative treatments,⁹⁷ securing second opinions,⁹⁸ finding a treatment centre offering treatment that is innovative, experimental, pioneering or at the 'frontier of medical science'.⁹⁹ The exercise of parental responsibility in the intensive parenting of a child in crisis may involve parents travelling with their child and family to another country in search of treatment,¹⁰⁰ selling belongings or otherwise raising funds for treatment.¹⁰¹ The internet has opened up to parents a wealth of information, of variable quality, about potential alternatives which might offer their child comparable prospects of recovery without exposure to the same levels of potential damage caused by standard treatment; stories of other parents accessing alternative treatments; and, charities offering financial support to do so. It may be difficult for parents to assess what information is relevant or reliable: uncertainty making care precarious. In response to the Trust's application for court authorisation for the administration of conventional post-operative treatment for cancerous brain tumour, medulloblastoma, Sally Roberts went missing with her son, Neon, seeking alternative, complementary, treatment which she believed would reduce the damaging long-term effects upon his

-
- ⁹⁶ <http://bindmans.com/news-and-events/news-article/terminally-ill-teenager-dies-following-right-to-life-legal-battle> [last accessed 02/09/16].
- ⁹⁷ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055; *An NHS Trust v SR* [2012] EWHC 3842; In one of the YouTube posts explaining their actions, Brett King told of how he had found out about Proton Therapy via the internet, Naveed King, 'Real Story of Ashya King', www.youtube.com/watch?v=14ETQn9ZPwk, posted 30/8/14, [last accessed 30/9/2015]; The judgment of Mostyn J in *Re JM (A Child)* [2015] EWHC 2832 referred to the parental wish for him to be treated with Chinese medicine.
- ⁹⁸ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055; *Re JM (A Child)* [2015] EWHC 2832. At its most extreme, in the case JS who wished to be preserved after her death in the hope that medical science would advance so that at some point in the future her body could be brought back to life and her cancer cured, *Re JS (Disposal of Body)* [2016] EWHC 2859.
- ⁹⁹ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055.
- ¹⁰⁰ Robert Mendick, 'It's the treatment that saved our son – so why did the NHS deny it to Ashya?; The story of one brain cancer survivor has given fresh hope to the desperate family of Ashya King', *The Sunday Telegraph*, 7/9/14, 13, <http://www.telegraph.co.uk/news/health/11078557/Proton-treatment-saved-our-son-why-did-NHS-deny-Ashya.html> [last accessed 27/10/16].
- ¹⁰¹ Whilst Ashya was receiving treatment in Prague and before NHS England had announced that they would be paying for it, the Daily Mail reported the decision of the parents of Frankie-rose Lea to put their house on the market to raise the money to take her abroad for treatment, having raised £20,000 through a fundraising page, Kelly Strange, 'Couple in desperate race to sell family home in next week to fund daughter's cancer treatment after doctors say she won't live until Christmas without it', *MailOnline*, 14/11/14, <http://www.dailymail.co.uk/health/article-2834450/Couple-desperate-race-sell-family-home-fund-daughter-s-cancer-treatment-doctors-say-won-t-live-Christmas-without-it.html> [last accessed 27/10/16]. Readers donated £176000, paying for the family to travel to Oklahoma for her to receive treatment, Kelly Strange, "'Overwhelmed" family of little girl battling cancer will no longer have to sell their home after strangers donate £176,000 in one weekend to fund life-saving treatment', *MailOnline*, 17/11/14, <http://www.dailymail.co.uk/health/article-2837639/Overwhelmed-family-little-girl-battling-cancer-no-longer-sell-home-strangers-donate-176-000-one-weekend-fund-life-saving-treatment.html> [last accessed 27/10/16].

quality of life; it was reported that his doctors had told his parents that the recommended radiotherapy would 'fry his brains'.¹⁰² The standard treatment necessary to ensure the eradication of cancerous cells, radiotherapy, risks serious side-effects including intellectual and cognitive impairment, effects upon growth, thyroid (which may cause lethargy or weight gain) and sub-, or in-, fertility, and risks secondary cancers in later life.¹⁰³ Bodey J invited the mother to provide the court with two papers which supported her view of reports from China or Russia of children surviving without mainstream treatment. The judge concluded that the two papers she identified did not provide evidence to support her claim and authorised the administration of conventional treatment.¹⁰⁴

The individual experience of parenting a child with cancer occurs within specific social and cultural contexts of parenting a child with a serious illness. These accounts expose parents to possibilities and to details of the lengths to which other parents have gone in their search for the best possible treatment, care and future for their child.¹⁰⁵ The media reports parents accessing alternative treatment for their child, legal challenges, efforts to raise money to travel abroad,¹⁰⁶ charities providing funds for treatment abroad or, through publication of their plight, receiving aid from benefactors or public donations. Captured on the internet, such stories remain to become a database of 'information' accessible to parents, setting parameters for 'responsible' parenting of a seriously ill child. As Mary Dixon-Woods et al observed in their comparison of the accounts of mothers with media accounts of children with cancer, the latter 'access and (re)create the dominant metaphors and terms within which the public discourse around childhood cancer can be conducted'.¹⁰⁷ The media, they noted, privileged some accounts such as the bravery of the child and the forces battling the evil cancer. Other accounts were silenced, such as the complex range of emotions of the child, conflicting responsibilities and parental needs.¹⁰⁸ Their comparison led them to the conclusion that media accounts, which will include those of courtroom

¹⁰² Andrew Hough, 'Sally Roberts: runaway mother will 'allow radiotherapy if son's cancer is back'' *The Telegraph*, 9 December 2012, <http://www.telegraph.co.uk/news/health/news/9733803/Sally-Roberts-runaway-mother-will-allow-radiotherapy-if-sons-cancer-is-back.html> [last accessed 27/10/16]; Channel 4, *You're Killing My Son: The Mum who went on the Run*, 13 August 2013.

¹⁰³ *An NHS Trust v SR* [2012] EWHC 3842, [18-19].

¹⁰⁴ *An NHS Trust v SR* [2012] EWHC 3842, [14]. Bodey J set out what the court would need to be satisfied of before it would authorise non-conventional treatment, [25].

¹⁰⁵ Jayme Bowen, *Panorama, The Story of Child B*, 26 October 1995, the journalist, Sarah Barclay, published *Jaymee; The Story of Child B*, 1996; Neon Roberts, *You're Killing My Son: The Mum who went on the Run*, Channel 4, 13 August 2013, Ashya King, *Ashya – The Untold Story*, BBC 1, 10 April 2015.

¹⁰⁶ Contemporary news reports, still accessible via the internet, of the removal of Ashya King from Southampton General drew on the experience of Alex Barnes whose parents had also found out about Proton Beam Therapy via a search of the internet and raised the money for his treatment in Florida, contrary to the advice of his treating doctors, Robert Mendick, 'It's the treatment that saved our son – so why did the NHS deny it to Ashya?; The story of one brain cancer survivor has given fresh hope to the desperate family of Ashya King', *The Sunday Telegraph*, 7/9/14, 13, <http://www.telegraph.co.uk/news/health/11078557/Proton-treatment-saved-our-son-why-did-NHS-deny-Ashya.html> [last accessed 27/10/16]. Their website aims to offer help and advice to people who wish to know whether Proton Therapy offers better treatment, <http://www.alexbarnesproton.com/>.

¹⁰⁷ Mary Dixon-Woods, Clive Seale, Bridget Young, Michelle Findlay and David Heney, 'Representing childhood cancer: accounts from newspapers and parents' (2003) 25 *Sociology of Health & Illness* 143-164, 161.

¹⁰⁸ Mary Dixon-Woods, Clive Seale, Bridget Young, Michelle Findlay and David Heney, 'Representing childhood cancer: accounts from newspapers and parents' (2003) 25 *Sociology of Health & Illness* 143-164, 162.

battles over decisions about the medical treatment of children with cancer, prescribed norms of managing response to threats to childhood' which can create 'public expectations and stereotypes that are difficult for parents and children to fulfil.'¹⁰⁹

A Parental Concerns, Conflict with Professionals, Court Intervention

Whilst being highly unusual at the time, as a parental challenge to medical decisions about the treatment offered to his child, and a judicial review of the decision of the health authority not to fund further treatment, in many respects the case of Jaymee Bowen is a paradigm example of parental concerns, conflict with professions and inconclusive intervention by the court. In January 1995, Jaymee suffered a relapse after a period in remission following treatment for acute myeloid leukaemia as a secondary cancer following treatment for non-Hodgkin's lymphoma.¹¹⁰ Her father, David Bowen, was told by the doctors treating Jaymee at Adenbrooke's, with whom doctors at the Royal Marsden where Jaymee had earlier undergone a bone marrow transplant agreed, that no further treatment was available and that she only had 6-8 weeks to live.¹¹¹ They were of the view that it was in Jaymee's best interests to be given palliative care, minimising pain and suffering with the aim of enabling her to enjoy what remained of her life. Her father set about searching for alternative treatment. Using the library at the Royal Society of Medicine, David Bowen researched leukaemia and its treatment locating doctors in California who were prepared to perform a second bone marrow transplant.¹¹² He did not have the funds to pay for this treatment. Further research led him to a specialist in adult leukaemia, Professor Goldman, who was prepared to treat but his ward, at the Hammersmith Hospital, had no available beds. In turn, Professor Goldman recommended Dr Gravett at the private Portland Clinic. In contrast with the palliative care recommended by the paediatricians who had been caring for Jaymee, her father had found further treatment, which doctors in the US, an adult specialist, and private provider, were prepared to administer. David Bowen sought to persuade the paediatricians to change their minds by sending the information he had gathered in a 'snowstorm of faxes'¹¹³ making demands of the consultants, for example that they study the literature on the US trials. In an increasing 'atmosphere of mistrust',¹¹⁴ he wrote to Cambridge District Health Authority requesting an extra-contractual referral. He was informed, in a letter from the Director of Health Policy, Dr Zimmern, of the decision of the Authority declining to pay. Dr Zimmern's policy was to refuse to meet patients or families seeking an extra-contractual referral in order to maintain objectivity but he lost that by hearing directly from the clinicians.¹¹⁵ To her father, the individuals responsible seemed to be distancing themselves from the effect of their decision which was to deny his daughter a chance of life-saving treatment.

¹⁰⁹ Mary Dixon-Woods, Clive Seale, Bridget Young, Michelle Findlay and David Heney, 'Representing childhood cancer: accounts from newspapers and parents' (2003) 25 *Sociology of Health & Illness* 143-164, 162.

¹¹⁰ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055.

¹¹¹ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055. Jaymee was first diagnosed at the age of 6 and had already undergone two courses of chemotherapy, total body irradiation and a bone marrow transplant. Her younger sister, Charlotte, was the donor raising questions about the duties of parents in balancing the best interests of their children.

¹¹² Chris Ham & Susan Pickard, *Tragic Choices in Health Care: The case of Child B*, King's Fund, 1998, 2-3.

¹¹³ Chris Ham & Susan Pickard, *Tragic Choices in Health Care: The case of Child B*, King's Fund, 1998, 31.

¹¹⁴ Chris Ham & Susan Pickard, *Tragic Choices in Health Care: The case of Child B*, King's Fund, 1998, 31.

¹¹⁵ Chris Ham & Susan Pickard, *Tragic Choices in Health Care: The case of Child B*, King's Fund, 1998, 69.

Communication about her treatment with those he had relied upon for her medical treatment and care had broken down. With differing opinions about further treatment being held by specialists in the US and the UK, evidence based treatment protocols in the NHS and the willingness to depart from protocol to use innovative and as yet unproven treatment in the private sector, between the paediatrician's focus upon a holistic analysis of her best interests and the adult specialists willingness to treat to prolong life, David Bowen lost trust in Jaymee's treating doctors.¹¹⁶ As the health authority refused to engage with him about their decision and in the absence of a formal internal mechanism for review, or challenge, or any help or advice, his only option was resort to the law.¹¹⁷ In their analysis of the case, Chris Ham and Susan Pickard suggest that resort to court may have been avoided had the health authority provided David Bowen with an explanation for their decision; had there been support available to enable him to understand the conflicting medical opinions; had there been counselling; a means of challenging or appealing against the decision; or, alternative dispute resolution.¹¹⁸

The decision that no further active treatment should be provided was based upon Jaymee's medical best interests weighing the chances of success against the likelihood of suffering and the view of her treating doctors that the treatment was experimental, offered only a very limited chance of success, and that palliative care offered Jaymee the best quality of life and would enable her to enjoy the rest of her life and to die in peace and dignity.¹¹⁹ Judicial review proceedings reviewed the decision-making process but not the reasons or justification for the decision.¹²⁰ Consequently, the judgment of the Court of Appeal appeared even further distanced from the needs and best interests of Jaymee herself. Whilst Laws J quashed the decision of the health authority on the grounds that it infringed her right to life and hence the authority had to provide 'substantial objective justification on public interest grounds', that afternoon, the Court of Appeal allowed the appeal.¹²¹ Thus, there had been no review of the merits of the treatment still on offer in the private sector. As David Price has argued the issue seemed no longer to be about Jaymee's best interests but was presented, to and by the court, in terms of 'costs, benefits, and resource availability', terms by which her father was not going to be persuaded.¹²²

Court intervention, therefore, did nothing to persuade Jaymee's father that palliative care rather than further treatment was in her best interests. Yet, despite not persuading the health authority and an unsuccessful court challenge, her father through his 'relentless efforts' achieved the result he had been fighting for and believed was best for his daughter, her further treatment. Newspapers, which reporting the health authority's decision as the callous result of a service driven by market principles, established appeals for her treatment.¹²³ An anonymous benefactor funded her further treatment. Jaymee was one of the first children to have the experimental treatment,

¹¹⁶ Chris Ham & Susan Pickard, *Tragic Choices in Health Care: The case of Child B*, King's Fund, 1998.

¹¹⁷ Chris Ham, 'Tragic choices in health care: lessons from the Child B case' (1999) 319 BMJ 1258- 1261, 1260.

¹¹⁸ Chris Ham & Susan Pickard, *Tragic Choices in Health Care: The case of Child B*, King's Fund, 1998, 80.

¹¹⁹ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055.

¹²⁰ Chris Ham, 'Tragic choices in health care: lessons from the Child B case' (1999) 319 BMJ 1258-61, 1260.

¹²¹ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055, 1060. Andrew Pierce, 'Family of leukaemia girl prepares her for last chance of life' *The Times*, 13/3/95, 3; Simon Jenkins, 'Life and death is not for lawyers' *The Times*, 11/3/95, 16.

¹²² David Price, 'Lessons for health care rationing from the case of child B' (1996) 312 BMJ 167-169, 168.

¹²³ Vikki Entwistle, Ian Watt, Richard Bradbury and Lesley Pehl, 'Media coverage of the Child B case' (1996) 312 BMJ 1587-1591, 1588.

donor lymphocyte infusion, using blood cells donated by the original bone marrow donor, her younger sister, Charlotte. Jaymee went into remission and the NHS took over her routine care.¹²⁴ Jaymee died, just over a year after the treatment commenced, in May 1996.

More usually, others with an interest in the welfare of the child who disagree with the exercise of parental responsibility in making decisions about a child's medical treatment refer the matter to court. Differences of opinion about the medical treatment of a child are usually brought to court by the NHS Trust or local authority who wish to obtain authorisation for the provision of treatment contrary to the decision of the child's parents. The duty of the court in such cases is not to exercise parental responsibility but to make an independent and objective decision, in the exercise of its protective jurisdiction,¹²⁵ about the welfare of the child. However, neither does court review of the merits of treatment, at least those which fail to consider parental experiences or address parental concerns, appear to persuade parents that the judge was better placed to determine the best interests of their child. The judge might hope, as did Holman J in *An NHS Trust v A*, that the parents may be persuaded by, or respecting the authority of the court abide by, the ruling of the court. An unusual feature of that case was that, although Baby A had spent a number of months in PICU, at the time of the application to court for authority to carry out a Bone Marrow Transplant (BMT), which her parents were refusing, A was not in hospital. A was being cared for by her parents at home and, following earlier treatment, was in remission. A BMT had to be carried out whilst her condition was inactive and it could become active again at any time.¹²⁶ A BMT whilst 'pioneering and evolving treatment' was world-wide standard treatment for the condition from which she suffered. It was also lengthy, painful, distressing, invasive and risky. Her parents refused their consent to a BMT concerned to spare their daughter the pain and suffering she had experienced during previous treatment, wishing her to enjoy the quality of life she then had and holding on to a belief that a miracle might cure her. Holman J noted that her parents retained 'final control over whether A undergoes a BMT or not' as it required hospitalisation and there was no suggestion that the court should order her parents to take her to hospital for a BMT or that she should be removed from them by an order of the court.¹²⁷ The judge continued,

'the parents are deeply law-abiding people who clearly respect the authority of this court and, I hope, its objectivity and wisdom. And they have said that if I do grant the declaration which the hospital seek, then they will most probably feel that they should respect it and co-operate in the BMT taking place.'¹²⁸

¹²⁴ Sarah Barclay, published *Jaymee; The Story of Child B*, 1996, 154. Subsequently, her father asked for the order he had previously requested to protect her anonymity, so Jaymee did not discover that she was 'Child B', to be discharged to enable him to use the media to raise money should Jaymee require further treatment and the broadcast of the Panorama documentary, *The Story of Child B*. Discharging the order, Sir Thomas Bingham MR, the same judge who had decided the earlier appeal commented, 'I greatly regret the necessity to exploit the medical problems of this child for purposes of financial gain. I do not, however, think that the maintenance of a reporting restriction could be justified if the consequence were the denial of treatment which might and, in the father's judgement, would be of therapeutic and possibly life-saving benefit to the child.' *R v Cambridge District Health Authority ex p B (No 2)* [1996] 1 FLR 375.

¹²⁵ Under the court's inherent jurisdiction, wardship or in a section 8 specific issue order under the Children Act 1989.

¹²⁶ *NHS v A* [2008] 1 FLR 70, [9], [14]-[22].

¹²⁷ *NHS v A* [2008] 1 FLR 70, [2].

¹²⁸ *NHS v A* [2008] 1 FLR 70, [2].

With this expression of hope, Holman J gave the declaration authorising the BMT. A postscript to the judgment noted that A died at home about two weeks later before any treatment could commence.

Rarely, parents are persuaded by the medical evidence presented to the court and consent to the course of action proposed by their child's doctors. The specific issue order put to the judge during the course of the hearing in *Re MM* was agreed by the parties, reflecting the acceptance by the child's parents of the advice of his doctors despite retaining their anxieties about the treatment.¹²⁹ Where the disagreement is as to the treatment that is in the best interests of the child, the independent assessment of the court very rarely agrees with the child's parents, more usually it is the medical evidence that prevails.¹³⁰ Parents who remain unpersuaded by the conclusion of the court may appeal or, in their relentless efforts to secure what they believe is best for their child, fail to comply with the order of the court. Given the urgency of the situation, Wilson J rejected the complaint of C's parents that the local authority had instituted legal proceedings before a full discussion of the issues surrounding their objection to having her blood tested to determine if she was HIV positive. The judge observed that the hearing had involved a:

'long and intelligent discussion of the issues relating to the treatment of a baby between knowledgeable parents on the one hand and two top-flight consultants on the other. It was almost as if the rest of us were flies on the wall of the consulting rooms at Great Ormond Street Hospital and at St Marys. Each doctor was questioned on behalf of the parents for about three hours; and the questions, both from Mr Horowitz on behalf of the mother and from the father himself, were admirable in every way. So also, as I have concluded, were the answers.'¹³¹

Prior discussion could have occurred in an environment that felt less adversarial and may have addressed parental concerns enabling them to agree a mutually acceptable solution to the disagreement. The courtroom discussion, however, failed to persuade the parents of the view of the doctors or court. They requested permission to appeal the order of the court authorising the test. When the Court of Appeal considered their application, three days before the test was due to be performed, the parents and child could not be located and were believed to have left the jurisdiction. The judgment of Wilson J had focused upon the welfare of the child, as required by the Children Act 1989 when determining a specific issue, and her rights, with reference to Articles 5, 6 and 24 of the UNCRC. Butler-Sloss LJ focused upon the welfare principle as the mechanism through which to protect the rights of the child.¹³² Yet, the judgments of the court, focused upon the baby's welfare and rights did not persuade her parents. The mother was quoted in the press expressing the view that parents should make decisions on behalf of their child and speak for them until the child is old enough to make her own decisions and objecting to state intervention into family life.¹³³ C was eventually tested a couple of years later and following the death of her mother. She tested HIV positive. C and her father returned to Britain. Some three years after the

¹²⁹ *Re MM (Medical Treatment)* [2000] 1 FLR 224.

¹³⁰ Whilst the decision of Baker J in *King* may at first sight appear to be an exception, it is important to appreciate that the judge did not conclude that the treatment Ashya's parents wanted him to receive was in his best interests. The medical evidence was that it was considered to be no better but no more detrimental than conventional treatment. It was in Ashya's best interests to receive post-operative treatment as soon as possible and that was best facilitated by approving his parents' plans for his treatment given that there was a treatment centre willing to provide it, transport and funding in place.

¹³¹ *In re C (A Child) (H.I.V. Testing)* [2000] 2 WLR 270, 275.

¹³² *Re C (HIV Test)* [1999] 2 FLR 1004, 1020.

¹³³ Angela Levin, 'HIV-test couple flee abroad with daughter', *Daily Mail*, 18/9/99, 19.

court order, C was made a ward of court placing responsibility for future decisions about her care with the court.¹³⁴

Parental concerns, a breakdown in the parent/professional relationship and inconclusive court proceedings are all in evidence in the case of *Re T*. The relationship between T's mother and consultant paediatrician Dr A at hospital X to which 18 month-old T had been referred for a liver transplant operation, at the time considered to be major surgery and more complicated than other transplant operations then available, became 'strained' when his mother refused her consent for reasons which Dr A 'could not accept'.¹³⁵ The mother's refusal was 'much influenced' by the pain and distress caused to her son by an operation he had undergone when only a few weeks old. Dr A told T's mother that the hospital would seek legal advice if she did not consent. The mother sought a second opinion from Dr P at another liver transplant centre, hospital Y. Dr P urged her to consent but was of the opinion that if, after further consideration, the mother continued to refuse that should be respected.¹³⁶ Dr A's team put T on the urgent transplant list but the mother had taken T to country AB where his father was working. A liver became available but the family could not be contacted. Believing that T's mother was not acting in his best interests, Dr A sought legal advice.¹³⁷ The local authority sought leave to commence proceedings under s.100(3) of the Children Act 1989. Connell J concluded that it was in T's best interests to undergo the transplant operation, gave permission for it to be performed despite his mother's refusal and directed them to return to the jurisdiction within 21 days for assessment at hospital Y or Z, although because of the breakdown in the relationship not at hospital X. The judge expressed the hope that the mother might change her mind and gave permission to appeal. The family remained outside of the jurisdiction whilst the matter was under appeal. Recognising in her judgment the mother's concerns about the transplant operation, Butler-Sloss LJ further explained that the uncertainty created by the child being outside the jurisdiction and as to whether hospital Z would operate if the mother continued to refuse were 'relevant' but not 'determinative' to her decision to allow the appeal.¹³⁸

The parents of ten year-old JM likewise responded to the disagreement with his treating professionals and the prospect of the decision being removed from them and being taken by the court by leaving the jurisdiction. JM's parents notified the court in advance that they would not be attending the hearing. Mostyn J made an order in recitals urging the parents to attend so that the court could hear their views and JM's treatment could be collaboratively determined.¹³⁹ The family could not be located for the order to be served. Judgment of the court authorising the surgery was therefore given in the absence of JM or his family who were believed to be in Poland seeking a second opinion about surgery to remove an aggressive form of facial cancer, craniofacial osteosarcoma.¹⁴⁰ Mostyn J noted the concern of JM's parents who, in the

¹³⁴ Lorna Duckworth, 'Girl Denied HIV Therapy by Father is put into care', The Independent, 9/5/02, 5 <http://www.independent.co.uk/life-style/health-and-families/health-news/girl-denied-hiv-therapy-by-father-is-put-into-care-9224068.html> [last accessed 27/10/16].

¹³⁵ *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242, 246.

¹³⁶ *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242, 246.

¹³⁷ *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242, 246.

¹³⁸ *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242, 252. The decision of the Court of Appeal, to leave with his parents the decision whether T had a liver transplant, has been subjected to much criticism, Andrew Bainham, 'Do Babies Have Rights?' (1997) 56 CLJ 48; Michael Freeman, 'Can we leave the best interests of very sick children to their parents?' in Michael Freeman (ed), *Law and Medicine, Current Legal Issues 2000*, OUP: Oxford, 2000, 257-268.

¹³⁹ *Re JM (A Child)* [2015] EWHC 2832, [11].

¹⁴⁰ *Re JM (A Child)* [2015] EWHC 2832. Requiring Mostyn J to address issues of jurisdiction *Re JM (A Child)* [2015] EWHC 2832, [16-17].

knowledge that JM did not want the operation, feared that he would blame them for the consequential facial disfigurement if they did give their consent. The judge quoted Dr X, JM's paediatric oncologist, who explained that she whilst she had told JM's parents that without surgery JM would not survive she did not feel that they had processed this information, in her view they had 'struggled with the consent process'.¹⁴¹ But there is no consideration as to why that may be nor of the steps which could be taken to address their difficulties. Mostyn J expressed the view that it was 'unfortunate' that the parents had not engaged with the proceedings of the court, that their collaboration with the surgery was 'essential' and their support post-operatively was vital such that if it was not forthcoming the Trust would need to return to court for further orders.¹⁴² The judge expressed the hope that they would read the judgment and 'actively support' his decision. At the last report of hearings in this case, two months later, MacDonald J was told that JM was expected to return to England with his mother later that month.¹⁴³ There is no report as to whether he did or whether JM has had the surgery considered by Dr X at the time of the court hearing urgently necessary to prevent a 'brutal and agonising death'.

A range of legal proceedings and court orders were made to ensure the post-operative treatment of Neon Roberts, even though his father was consenting to the recommended treatment. Concerned that the mother of Neon Roberts was 'disengaging' and putting him at grave risk by missing appointments with the consequence that he had not commenced radiotherapy within the optimum time for positive results, the Trust applied, without notice, for orders regarding his treatment. However, the order made for his mother to attend court the next day could not be served as she had disappeared taking Neon with her.¹⁴⁴ Media publicity led to them being tracked down and Neon was placed in the care of his father who consented to conventional treatment.¹⁴⁵ The issue of post-operative treatment was overcome by a more pressing issue when a scan revealed a cancerous tumour in the surgical cavity which required further surgery. The mother sought a second opinion, agreed to surgery, then refused her consent. Bodey J made an order authorising surgery, against which the mother appealed. Ward LJ heard further evidence including a further second opinion on behalf of the mother, which supported treatment, and refused her appeal.¹⁴⁶ Bodey J recognised that it had been a very stressful time for Neon's parents observing that: 'What the parents have suddenly had to confront over the past two or three months is every parent's nightmare', but agreed with Ward LJ that the mother was becoming 'increasingly implacable', 'her approach has hardened as these stressful days in court have gone on' and that she was 'somewhat overwhelmed by the process'.¹⁴⁷ With his mother strongly expressing her objection to conventional treatment and of the view that she was fighting for her child against the system,¹⁴⁸ Bodey J made orders authorising the treatment package and ancillary care, authorising clinicians to act on consent of his father alone, a residence order in favour of the father, a contact order with his mother and prohibited steps orders preventing the mother from removing Neon from the father's care during his treatment or applying for a passport.¹⁴⁹

Likewise, the parents of five year-old Ashya King took extreme steps in the attempt to secure the treatment they considered to be in his best interests, prompting

¹⁴¹ *Re JM (A Child)* [2015] EWHC 2832, [10].

¹⁴² *Re JM (A Child)* [2015] EWHC 2832, [12].

¹⁴³ BBC News, 'Boy needing urgent cancer surgery is in Poland, court hears', 21/12/15 (last accessed 27/1/17).

¹⁴⁴ *An NHS Trust v SR* [2012] EWHC 3842, [4].

¹⁴⁵ *An NHS Trust v SR* [2012] EWHC 3842, [4-7].

¹⁴⁶ *An NHS Trust v SR* [2012] EWHC 3842, [8-12].

¹⁴⁷ *An NHS Trust v SR* [2012] EWHC 3842, [22].

¹⁴⁸ Neon Roberts, *You're Killing My Son: The Mum who went on the Run*, Channel 4, 13 August 2013.

¹⁴⁹ *An NHS Trust v SR* [2012] EWHC 3842, [27-29].

a range of public interventions. Within hours of his diagnosis, Ashya's parents had given their consent to surgery to remove a malignant brain tumour, medulloblastoma. Surgery left him with an acquired brain injury, paralysed, unable to communicate or swallow.¹⁵⁰ Ashya's parents wished for him to be provided with Proton Therapy which they had discovered from a search of the internet and believed would cause fewer long-term detrimental effects upon his future quality of life than conventional radiotherapy and chemotherapy. Proton Therapy was not then available in England.¹⁵¹ The hospital had applied to NHS England which funds treatment abroad of patients who meet the criteria in the National Specialist Commissioning Team guidance¹⁵² but, applying this guidance, the NHS England Proton Clinical Reference Panel declined to fund treatment for Ashya. His doctors could, therefore, only offer conventional, clinically tested, post-operative chemotherapy and radiotherapy. Dr Shad, a member of the team treating Ashya acknowledged the centrality of a good relationship between the parents of a child with a life threatening condition and the treating doctors so that parents trust the team providing the medical care.¹⁵³ The trust between Ashya's parents and treating team had disappeared.¹⁵⁴ Brett King explained that they felt that they were given inconsistent information about the protocols being followed and the treatment plan. Furthermore, Ashya's parents felt that their attempts to communicate with his doctors about the alternative treatment they wanted him to have were ignored. And, further, they felt they could no longer discuss Ashya's treatment with his doctors believing that if they questioned the treatment planned for him the Trust would seek an emergency protection order preventing his parents from having contact with him and enabling the local authority to make decisions about Ashya's treatment.¹⁵⁵ This was disputed by the Trust. Brett King claimed that their request for Ashya's medical records to be sent to the clinic in Prague, which would have enabled them to give their

¹⁵⁰ Side effects of brain surgery for medulloblastoma, cerebellar mutism syndrome initially rendered him unable to move his limbs, head or eyes and bulbar palsy affected his mouth and tongue making it difficult for him to swallow and necessitating nasogastric feeding, *In the Matter of Ashya King* [2014] EWHC 2964, [7].

¹⁵¹ *In the Matter of Ashya King (A Child)* [2014] EWHC 2964. Except low energy proton therapy specifically for patients with eye tumours at The Clatterbridge Cancer Centre NHS Foundation Trust. Two centres are in the process of construction, in Manchester (due to open in 2018) and London (due to open 2019), <https://www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt/> [last accessed 1/9/16]. Centres are also being built by private providers, making inevitable disputes over funding in the future, <http://scienceblog.cancerresearchuk.org/2015/07/16/proton-beam-therapy-where-are-we-now/> [last accessed 1/09/16].

¹⁵² At centres in Villigen (Switzerland), Jacksonville and Oklahoma (USA), National Specialised Commissioning Team, *Guidance for the Referral of Patients Abroad for NHS Proton Treatment*, July 2011 www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b01/ [last accessed 1/09/16], 7.8.

¹⁵³ 'Ashya Doctor: We regret communication breakdown', https://www.youtube.com/watch?v=LBy_-jAqbo8 (last accessed 9/8/16).

¹⁵⁴ A Portsmouth Safeguarding Children Board Review was later to conclude that staff had worked hard to achieve a partnership with the parents but that there was a breakdown in trust which left the questions whether there was any way in which this could have been avoided ie by holding a formal meeting or second opinion. The review recognised that parents need to feel that they have 'explored all possible avenues' and professionals should 'examine their actions from the point of view of the parent and child', Portsmouth Safeguarding Children Board, *Executive Summary of the Lessons Learned from a Review of Inter-Agency Working with a Child in Acute Care*, Sept 2015, 2.4.

¹⁵⁵ Naveed King, 'Real Story of Ashya King', www.youtube.com/watch?v=14ETQn9ZPwk, posted 30 August 2014, [last accessed 9/8/16].

opinion on his treatment, was ignored.¹⁵⁶ His parents asked Southampton for a private referral to the Proton Therapy Centre in Prague which had treated cases of medulloblastoma and was willing to treat Ashya but they did not, at that time, have the funds to pay for his treatment. So they made the necessary arrangements and removed him from hospital, without the knowledge of his treating doctors, to secure the funds to pay for his private treatment. At this point, genuinely concerned for his welfare, believing that his parents were not able to use the pump administering food, a European Arrest Warrant was issued and Ashya was made a ward of court. After a police hunt and much critical media attention, the family were located in Spain. Deciding upon his treatment in wardship proceedings, Baker J was not by this stage resolving a dispute as Southampton General did not oppose the provision of Proton Therapy if the arrangements were in place. Persuaded that there was a 'reasonable and coherent alternative treatment plan' for the provision of the post-operative care Ashya now urgently needed, with funding and transport arrangements not opposed by the local authority, CAFCASS or the hospital trust, Baker J authorised his treatment in Prague.¹⁵⁷ As with the earlier case of Jaymee Bowen, there is little analysis in the judgment of which medical treatment, the clinically proven conventional treatment or the 'innovative and as yet unproven therapy'¹⁵⁸ Proton Therapy, was best for Ashya.

Thus, the parental concern to secure what they believed was the best treatment for their son, to minimise the long-term damaging effects of the treatment that was necessary to save his life, occurred within the context of a breakdown in communication and trust and fear of a threat of an application to court which would remove from his parents their decision-making responsibilities. Thus his parents took drastic measures but measures that secured the treatment they considered to be best for him, an outcome which would have been highly unlikely had Ashya still been in Southampton when decisions about his treatment were made by the court. NHS England subsequently funded his treatment, authorised by the court in wardship proceedings.¹⁵⁹ Headline cases such as this played out so publicly can raise for parents of children subsequently diagnosed questions about the treatment provided to them and whether there are better alternatives available. Within weeks of this high profile case clinicians reported that parents of children with cancer were increasingly questioning whether the best care was being offered to their child.¹⁶⁰ Yet, the best treatment for each child is dependent upon a range of factors:

'Deciding on the right type of cancer treatment is incredibly complex... It is dependent on multiple variables such as the type of tumour, the grade of the

¹⁵⁶ Naveed King, 'Real Story of Ashya King', www.youtube.com/watch?v=14ETQn9ZPwk, posted 30 August 2014, [last accessed 9/8/16].

¹⁵⁷ *In the Matter of Ashya King (a Child)*, PO14C00645, 5 September 2014; *In the Matter of Ashya King* [2014] EWHC 2964. Wardship was then discharged.

¹⁵⁸ The National Specialised Commissioning Team guidance notes the 'considerable recent media and internet interest in proton therapy for children' but cautions that despite some studies predicting advantages compared with conventional therapy, these have not yet been established in clinical research trials, National Specialised Commissioning Team, *Guidance for the Referral of Patients Abroad for NHS Proton Treatment*, July 2011 www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b01/ [last accessed 1/09/16], 10.5.

¹⁵⁹ Sarah Boseley, 'NHS to pay for Ashya King's care in Prague', *The Guardian*, 27/9/15, 8, <https://www.theguardian.com/uk-news/2014/sep/26/nhs-pay-ashya-king-proton-therapy-treatment> [last accessed 27/10/15].

¹⁶⁰ Sarah Boseley, 'Ashya King case could lead to families rejecting NHS advice, doctors warn', *The Guardian*, 12/11/14, <http://www.theguardian.com/society/2014/nov/12/ashya-king-nhs-advice-cancer-doctors> [last accessed 27/10/16].

tumour, the size and location, the age of the patient, his or her response to other treatments, and so on.¹⁶¹

Medical decisions about cancer treatment fall within the expertise of doctors. Decisions about a child's treatment fall to parents in the exercise of their parental responsibility. In the vast majority of cases, the responsibilities are not so clearly demarcated, the experience is of shared responsibility, a partnership of care in which parents will accept medical recommendations and variations necessary to meet the specific needs of the child are negotiated. Parental concerns about their child's medical treatment can however develop into a conflict of views. Conflict between those with the responsibility to care can distract focus from the child and is not in the child's best interests. Referring that conflict to court may result in the court authorising medically recommended treatment but, if that does not accord with parental views as to the best interests of their child, court orders do not guarantee that the child immediately receives that treatment.

A Supporting Parents of a 'child in crisis'

Parents of seriously ill children have always used all means available to secure the best possible treatments for their child. However, it is necessary to understand the reality of the practical exercise of parental responsibility for seriously ill children in the context of fast moving developments in medical science with easy access via the internet to accounts of risks, side-effects and alternative treatments and their 'success stories' and charities raising funds for research into new treatments and offering financial support to parents in their pursuit of them, if the circumstances are to be understood in which parental concerns about the medical treatment of their child may develop into disagreements and escalate into disputes. Dismissing the parental application to appeal three days before the court-authorised HIV test was due and when the whereabouts of parents and child were unknown, Butler-Sloss LJ expressed the view that for the parents to have pre-empted the test and left the jurisdiction with their daughter was 'somewhat irresponsible'.¹⁶² Her Ladyship opined that most people would consider the intrusion, of being required to take the child to hospital for a blood test, to be comparatively small but that the parents had 'magnified this into a major issue' because they rejected the mainstream medical view of HIV. For the parents it was a major issue. Flouting the order of the court by leaving the jurisdiction was what they felt to be necessary to protect their daughter's well-being.

If parents ignore the order of the court, professionals may be protected from a potential negligence claim or professional misconduct proceedings but the child may not receive the treatment he or she needs. In such circumstances, judicial intervention is a stage in the conflict but not its resolution. Court intervention is then a no-win situation; for child, parents or professionals. High conflict cases about the medical treatment of a seriously ill child have profound and lasting effects upon the child, their family, the clinicians involved¹⁶³ and long-lasting ramifications for children who are subsequently diagnosed and their families. A Code of Practice could detail how professionals may fulfil their duty of care and the Trust its responsibility to support parents to fulfil their parental responsibility ensuring that the interests of the child remain at the centre of care. Emphasis should be placed upon the clinical duty to provide the child with the best medical treatment working in partnership with the child's parents, as Rob Heywood has argued, upon shared care rather than removing

¹⁶¹ Dr Max Pemberton, 'Ashya belongs in Britain', *The Daily Telegraph*, 2/9/14, 17, <http://www.telegraph.co.uk/news/health/11068128/Ashya-King-should-be-treated-in-Britain.html>, [last accessed 29/10/16].

¹⁶² *Re C (HIV Test)* [1999] 2 FLR 1004, 1018.

¹⁶³ Very clearly articulated by the clinicians involved in the care of Ashya King in Southampton, Ashya King, *Ashya – The Untold Story*, BBC 1, Broadcast, 10 April 2015.

responsibility from parents by referring the decision to court.¹⁶⁴ Professional duties include the duty to respond to parental concerns, address their cause and seek to repair the relationship of trust with parents through the provision of information, support and advice.¹⁶⁵ Emphasis should also be placed upon the responsibilities of the Trust to support both parents and professionals to ensure the child gets the best possible care by employing strategies to reach consensus¹⁶⁶ such as involving other members of the healthcare team in discussions, offering support from, for example, PALS or religious or community leaders, directing parents to reliable sources of advice,¹⁶⁷ or counselling. Trusts should be under an obligation to take steps to ensure all options have been explored in the attempt to find a way forward to agreed treatment for the child, including securing a second opinion, referral to a Clinical Ethics Committee or the use of mediation or other alternative dispute resolution.¹⁶⁸ Alternative approaches have to be undertaken to respond to parental concerns arising from their relentless pursuit of the best possible treatment for their child. Court orders are not a panacea for the resolution of conflicts over care.

27th January 2017

¹⁶⁴ Rob Heywood, 'Parents and Medical Professionals: Conflict, Co-operation and Best Interests' (2012) 20 Medical Law Review 29-44.

¹⁶⁵ Liz Forbat, Charlotte Sayer, Phillip McNamee, Esse Menson, Sarah Barclay, 'Conflict in a paediatric hospital: a prospective mixed-method study' (2016) 101 Arch Dis Child 23-27, doi:10.1136/archdischild-2015-308814.

¹⁶⁶ Simon Meller, Sarah Barclay, 'Mediation: an approach to intractable disputes between parents and paediatricians' (2011) 96 Arch Dis Child 619-21, 619.

¹⁶⁷ The Kennedy Report recommended a system of 'kitemarking' so that the public could be assured that the information they were accessing was reliable and of good quality, *The Report of the Public Inquiry into children's heart surgery at The Bristol Royal Infirmary 1984-1995*, Cm 5207(I), 2001, 438.

¹⁶⁸ Simon Meller, Sarah Barclay, 'Mediation: an approach to intractable disputes between parents and paediatricians' (2011) 96 Arch Dis Child 619-21.